

FAMILIES AND INFORMATION-SHARING IN THE MENTAL HEALTH SYSTEM

by

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A MAJOR PAPER SUBMITTED  
IN PARTIAL FULFILLMENT OF  
THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF SOCIAL WORK

In the School of Social Work and Human Services

Clara Sitar 2012  
UNIVERSITY OF THE FRASER VALLEY  
Spring 2012

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## **List of Acronyms**

EE	Expressed Emotion
EPI	Early Psychosis Intervention (Program)
FAC	Family Advisory Committee
FOIPPA	Freedom of Information and Protection of Privacy
NAMI	National Alliance for the Mentally Ill
UBC	University of British Columbia
UFV	University of the Fraser Valley
VCH	Vancouver Coastal Health
VCMHS	Vancouver Community Mental Health Services

## **Abstract**

Family involvement in the mental health system has been identified as evidenced-based best practice in the treatment of people with mental illness. However, family involvement has not been widely embraced by practitioners, and it is suggested that family-blaming may play a role. Confusion around information-sharing policies has been documented as a barrier to interaction between clinicians and families. Therefore, addressing misconceptions around confidentiality may be the gateway to increased family involvement.

This research was conducted in two parts. Questionnaires and interviews, both taking place relatively independently of the other, were used as assessment tools related to the delivery of an education module. In order to assess if practitioner beliefs and practices around families can be altered by a workshop, questionnaires were completed by participants prior to the module, and five interviews were carried out after delivery of the module. The education module was presented by the researcher to three mental health teams in Vancouver. The module focussed on information-sharing policies, the experiences of families, and the concept of family-blaming. The interview participants were asked for feedback from the module and asked their views on families and family involvement.

The results had concurrence with the literature review, whereby a connection was identified between beliefs about families and practice with them. Therefore, clinicians who found family involvement beneficial to their clients tended to involve them in their practice, while clinicians who believed that family involvement was not beneficial tended not to involve families in their practice. Confusion exists regarding information-sharing policies, and clinicians are interested in having this clarified. The feedback from the module and an understanding of the beliefs of some practitioners will be helpful in planning future trainings.



### **Acknowledgements**

I wish to express gratitude for the dedication and wisdom of my major paper supervisor, Dr. Adrienne Chan, who also wonderfully supported me and our whole class through our research projects. Many thanks also to my second reader Dr. Lisa Moy for the insights she offered.

## Introduction

In the field of mental health, there are many participants. At the centre is the client, who is surrounded by services and helpers. In times of acute need there are emergency rooms, psychiatric wards, and step-down psychiatric facilities<sup>1</sup> where patients see a wide range of mental health professionals. For some of the most impaired clients there are group homes of all kinds, staffed by support workers. All of these facilities provide care for a small proportion of clients with mental illness at any given time.

The rest of the people with mental illness, or at least those receiving treatment, obtain their care in smaller portions: a two-hour therapy group; a visit to their mental health team with their case manager or psychiatrist, lasting no more than an hour; or an activity with a recreational therapist or a peer support worker. A client in crisis can receive brief mental health telephone support, but only so much, so often. And what of the other minutes, which stretch into hours, which stretch into days? Who fills that enormous void?

This paper begins with the premise that family members and other caregivers are vital to the well-being of those with mental illness, yet are often disregarded in the mental health system. Furthermore, they have no voice in it. And if they have no voice, shame and secrecy amongst friends, neighbours, and co-workers who know little about mental illness are reinforced. Professionals' ideas about families play a crucial role in the exclusion of these families from the mental health system itself. Arguably, it is through this very setting that families should be able to avail themselves of expertise, information, and understanding. Their experience of feeling unwelcome is evidenced by the 'fact' that there is typically no one whose job it is to contact families, introduce themselves as a resource person or case manager, ask how they are managing,

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<sup>1</sup> A step-down facility provides less restrictive care than a hospital setting to patients who do not require constant supervision and 24-hour nursing care, yet need short-term monitoring and support in order to help them stabilize.

and ask how they can be supported. Observations and experiences reveal that, with the exception of general information brochures available on some psychiatric wards, there is no one who explains our convoluted mental health system to families when they are traumatized by the ill health of a loved one, or tells them how they can be involved. Both research and my professional interactions with families and family advocates demonstrate that in the experience of many families, no one invites or encourages them to participate in the care of their loved one, asks for their opinion, or tells them about the treatment plan. No one provides basic, non-confidential information about their loved one. No one tells them their rights as caregivers, what to do if they have concerns about their loved one's treatment, or what recourse they might have if they do not agree with the treatment. Through this process the family or caregiver becomes a non-entity, and their voice is silenced because even though their contribution is significant, it has no formal portal into the mental health system. It will also be shown in the literature and the research that the family is frequently denigrated instead of valued through this process.

This paper will examine the experience and difficulties of families with mentally ill loved ones who participate in the mental health system. The paper will focus on the topic of information-sharing between mental health professionals and families, and it will be revealed that perspectives on families affect collaboration between these two groups. The research described in this paper is focussed on the specific practice of clinicians in Vancouver Coastal Health (VCH) in the community mental health team setting, around information-sharing. Factors which affect their practices will be examined. A theoretical framework provides the basis for interpreting that which results from the literature review and the research. As part of the analysis, historical influences will be reviewed. Conclusions based on the research findings and their relation to other literature will be drawn, and implications for policy and practice will be

considered. An effort has been made to give families a voice in this paper, and this was congruent with the research process, even though families were not participants in the research.

Note that in this paper the term “families” is frequently used when discussing caregiving. This language should be understood to represent caregivers in general, which comprise a wide range of involved people such as grandparents, siblings, close friends, roommates, and neighbours. In fact, a caregiver can be anyone in the community who is functioning in that role or who is identified as such by a client.

### **Overview, Background, and Significance**

#### **Clinical Application of Confidentiality Policies**

The maintenance of client confidentiality is one of the “core social work values and principles” found in the Canadian Association of Social Workers’ *Code of Ethics* (2005). Social workers entering health care, however, find that in some cases they must use their discretion around this policy. The *Freedom of Information and Protection of Privacy Act (FOIPPA)* (1996) indicates that they must carefully keep most of their clients’ information confidential, but they can and they *should* share some of it in the best interest of their clients. Information-sharing is a distinct component of confidentiality guidelines in the health context, and refers to sharing need-to-know client information between two appropriate people, agencies, services and programs. This information sharing is conducted unquestioningly and automatically between health care providers, in order to offer the client appropriate care over time. For instance, when a client is transferred from one mental health case manager to another, the first clinician explains the client’s treatment history and plan, and provides other relevant information. This ensures that the transfer is as seamless as possible and the new case manager is prepared for the task instead

of starting from the very beginning with a client who has already been receiving community mental health treatment, possibly for many years.

Sharing of information is acceptable under the term “continuity of care” (BC Ministry of Health, 2005). Information-sharing of this nature is also completely appropriate, albeit with a lesser degree of detail, with families or significant caregivers, and is equally supported by the BC Ministry of Health (2005), not to mention the *Freedom of Information and Protection of Privacy Act (FOIPPA)* (1996). For instance, if a person develops mental illness, goes to hospital for treatment, and is sent home into the care of family, a transfer of information is required by the family in order to provide follow-up care of any kind. As Marshall and Solomon (2003) explain, the level of care which families can provide to their ill loved one is quite limited if these families are not given information on their relative’s condition and needs. Information families require for continuity of care, therefore, includes details about medications and side effects, what to do in an emergency, and how to best support the person considering his mental illness and his symptoms. As such information is readily available to family members in other health care settings, it can be argued that a double standard has been created. This double standard can be seen as rooted in a history of family-blaming by the professional mental health community (Davis, 2006, p. 85-87).

For some families, it appears as though clinicians use confidentiality guidelines as a way of avoiding working with them, even though they are such an integral part of the patient’s support system and are often even their caregivers (Davis, 2006, p. 88). Acts which exclude families from care planning and on-going treatment do not merely cause families to feel frustrated. When practitioners fail to communicate with families they are also failing their patients; these patients unavoidably receive inferior treatment if their caregivers are unprepared,

uninformed, or ill-equipped to help them—through no fault of their own (Marshall & Solomon, 2003). The BC College of Social Workers’ *Code of Ethics* (2003) states that working in the best interest of the client is the *primary* professional obligation, and while professional codes of ethics and practice guidelines can vary in a role which is carried out by nurses, psychiatric nurses, clinical counsellors, and occupational therapists, enhancement of client well-being cuts across them all. Therefore, choosing not to interact with caregivers out of preference, personal belief, or other reason which is not evidence-based or supported on a variety of levels is problematic. This then becomes an area for advocacy and education.

Chen (2008) summarizes the struggle of clinicians to practice according to policy as being a “fine line to walk” between helping families and risking their jobs. As such, it is not unreasonable to suggest that some practitioners are perhaps being overly careful, and are inadvertently neglecting families in the process. This is another example of the intricacy of the dilemma, and clinicians’ need for clarification of the actual rules—a need that has been identified by families and is now being heard. Given the complexity of the issue, however, its prevalence, and its power (for this is an issue in Australia, the USA and the UK as well, according to a brief survey of research databases [Chen, 2008; Rowe, 2010; Wynaden & Orb, 2005]) it remains to be seen what will be necessary to make a significant change.

While there is general awareness in health care settings about the need to maintain confidentiality, there remains a lack of training specific to the mental health field. Marshall and Solomon (2003) found, in their research on professional practice in mental health, that 95 percent of the clinicians they studied “interpreted confidentiality policies conservatively, [... and] 54 percent were confused about the types of information that are confidential” (p. 1622).

Within the Vancouver Coastal Health (VCH) Authority, in-depth training on information-sharing with families has yet to be provided to mental health clinicians. Indeed, this is illustrated by the fact that a research project of this nature was sought out by Vancouver Community Mental Health Services (VCMHS) to address this very gap. (VCMHS is an agency which directly oversees the community mental health teams, falling under the umbrella of VCH.) Anecdotally, mental health clinicians in Vancouver have expressed to VCMHS' administration their confusion and discomfort around information-sharing with families, particularly since expectations that they involve the families of their clients are ever-increasing. Arguably, the plethora of unique cases and situations clinicians encounter in this field makes it challenging for them to apply discretion around policies they do not fully understand. Despite the prevalence of the problem, the goal of impacting the practice of mental health clinicians through training is certainly not unrealistic. Krawitz (2004) studied the impact of a two-day training workshop for this group around working with borderline personality disorder (BPD) patients. Recent research has changed our understanding of BPD, allowing for a new perspective on these patients. The workshop that was used in Krawitz's research successfully challenged deeply ingrained beliefs and changed the practice of participants. At sixth month follow up, this change was still statistically significant.

### **The Roots of My Interest**

On a personal level and as a social worker, I am passionate about the rights and treatment (or *mistreatment*) of families and other caregivers in the mental health system. I consider myself lucky, in my work, to have seen the world of mental health from the family's perspective. I have seen the rich contributions that families make to the lives of their ill loved ones. I have also witnessed how errors made by case managers improperly applying information-sharing and

family involvement policies and practices can have devastating consequences for clients and their families.

I have also co-facilitated a psycho-educational group for families, created by the BC Schizophrenia Society, and have heard these dedicated family members share their troubling experiences of being excluded from the mental health system. I have thus seen what was believed of intelligent, well-balanced, and incredibly caring parents as caregivers during the psychiatric crises of their children. Additionally, someone I care about participated for a number of years in an informal self-help group of mothers with children who have mental illness. I met and formed relationships with some of these amazing women, women with heavy burdens that they somehow manage to carry—mainly because “you do what you have to in order to survive,” as the adage states. I have also seen the depths of mental illness in these women’s children, how they have had to alter their ways of being parents to those children, and how it has affected their families. So when I hear language like “enabling”, “enmeshed”, over-involved”, and “co-dependent”, I know those practitioners do not know what it is like to care for someone with serious mental illness when the shift is never over and there will be no one else ultimately picking up the pieces if things go wrong.

When I went into the health care field, I was immediately taught that the family is part of the client group. It is expected that when one member of the family is in a health crisis, other family members will be affected by the crisis and may need support because of it. Whether that assumption is held equally in mental health is rather debatable, yet there is no reason why it should be different. As a social worker, I see the plight of families and want immediately to advocate for them as a whole. To me it is shameful that their needs and rights seem to be afforded little importance in the system, particularly without justification in our current day and



age. This paper and the research it describes were designed to examine the matter in detail. I hope that my recognition of the competency and efforts of some mental health practitioners with regards to family involvement will be apparent; if at times I seem to suggest that all case managers avoid family involvement or view families negatively, it is not my intention to do so.

### **Research Objectives**

The broad objective of the research was to determine if an education module on confidentiality policies in a mental health setting, when delivered to mental health clinicians, could lead to (a) a change in professional beliefs and perspectives around working with families and clients, (b) a new awareness of their roles, the expectations of them, and appropriate information-sharing, and (c) altered practice with clients and families.

The research included the following objectives:

1. To identify clinicians' concerns around applying confidentiality policies, as they understand them, in their practice. This was required to create the module.
2. To identify clinicians' beliefs around applying confidentiality policies, as they understand them, in their practice. This was required to create the module.
3. To formally assess, prior to the intervention (the module delivery), participants' perspectives regarding the application of confidentiality policies in their practice.
4. To assess, post intervention, if:
  - i the intervention affected the participants' understanding of confidentiality policies, and their beliefs about it (as well as the value of working with families).
  - ii the intervention affected the participants' practice.

The issue of information sharing with families in mental health is quite complex. Since it is an issue in other English-speaking countries at least (no articles in other languages were

surveyed), the challenge to create change is far from insignificant. VCH is not alone in seeking to support its case managers in change around information-sharing.

This research allowed for the exploration of an issue that has important outcomes for policy and practice. The merit of family involvement has been previously identified and will be discussed shortly in the literature review. The need for family involvement to occur in ways which enhance the lives of clients has now become a focus of change for those in administrative roles and those on planning committees in health authorities such as Vancouver Coastal Health. Information-sharing in mental health is interesting because it has always been seen by families as vital, and seems to have *come to be perceived as* relevant and valuable to those more removed from frontline practice, yet it seems to remain less appreciated by many frontline workers.

### **Literature Review**

This literature review is organized into components which document relevant research in a number of areas. These include historical and present perceptions of families with a mentally ill relative and the predicament of families in the system. The latter is contrasted with the contributions of families to their loved one and the mental health system itself. The role of research, the specific issue of confidentiality, and relevant policies and clinician responsibilities around information-sharing are examined, as well as barriers to collaboration with families, strategies which have previously been tested to enhance family involvement, and ethical considerations.

### **Historical Perceptions of Families**

Views of families today, as they will be discussed in this literature review, need to be framed within an important and undeniable historical context. Neill (1990) writes in “Whatever Became of the Schizophrenogenic Mother?” that in the mid-twentieth century in the United

States, psychiatry took a strong “nurture” (as opposed to “nature”) approach to mental illness. In practice, this led to finding fault in the family for the unusual and misunderstood behaviours that resulted from psychosis. In 1948, Fromm-Reichman, quoted in Neill (1990), wrote that "the schizophrenic is painfully distrustful and resentful of other people due to the severe early warp and rejection he encountered in important people in his infancy and childhood, as a rule mainly the schizophrenogenic mother" (p. 500 ). Alanen (1969), in his research on mothers who had children with schizophrenia, ascribed to them a number of behaviours and symptoms including: emotionally rigid, schizoid and very aggressive, obsessive, insecure and highly anxious, bitter, lacking self control, emotionally chaotic, cold, unable to understand themselves in relation to others, dominating, and either psychotic in their own right or with behaviour and thoughts bordering on psychosis. The normal mother, then, was the exception instead of the rule.

The “double bind” was a further classic family-blaming theory, in which the parents supposedly gave their child contradictory messages (Davis, 2006). Another was the concept of damage caused by what was termed “schism and skew” in the marriage of the mentally ill person’s parents (Davis, 2006). Lefly (1996) and Neill (1990), looking back at that time period, explain that the studies which made these claims were flawed. For instance, they were biased, non-blind, and/or lacking a proper control group. However, Neill points out that the results of these flawed studies were treated as fact. Therapists in training learned to view families through this lens. These “facts” about families were disseminated to the public through media such as radio programmes, both as education and as entertainment, and they were also used as justification for imposing therapy on families (to correct the family pathology that causing the problem) and/or separating them from their ill loved one.

## **Problematic Perceptions of Families**

Pursuant to a history of blaming families in what are now recognized as unjust ways, the following section will also show a subtle yet similar theme. The unchanged family-blaming theme explains hesitancy on the part of some clinicians to work with families in mental health. The altered, subtle nature of family-blaming today may be the reason it is ill-recognized. The research conducted by Marshall, Solomon, Steber, and Mannion (2003) on practitioner beliefs suggested that family causation theory, while only being taught to training professionals up to the early 1990s, still persists in the present-day clinical setting. Instead of disappearing gradually over time, Marshall et al. show evidence that it may instead be perpetuated and reinforced in professional practice. The authors also explain that biological models and family causation models, while distinctly different, can be held by clinicians simultaneously, often with blurred boundaries. They may not even be aware of it. While the diathesis-stress model of mental illness states that a huge array of environmental factors can cause mental illness or relapse, a clinician who carries family causation beliefs will focus almost entirely on the family as the cause of illness. This focus denies the myriad of other biological and environmental possibilities which are currently considered to create mental illness, either alone or in combination (Austin, 2005). Fuller Torrey notes that no stressor is sufficient on its own to cause bipolar disorder (2002), and no study has proven that family trauma alone can cause schizophrenia (2006).

A modern family causation model is arguably that of “expressed emotion” (EE). Expressed Emotion refers to a mix of overt criticism, hostility, over-involvement, and over-identification within a family, said to create a toxic living environment which causes a family member with schizophrenia to relapse. In this model, relapse is seen to be particularly the fault of the mother and her behaviour (Fuller Torrey, 2006). King (2000) argues, however, that EE is

caused in the family by the ill relative's behaviour, not by the deviance of the family. The research of McFarlane and Cook (2007) shows that EE is not present in families *prior* to the first onset of psychosis, so EE is correlated to the onset of the illness. Davis (2006) cites a treatment guide for first-break psychosis from the University of British Columbia, which states that EE is not associated with relapse in early psychosis; rather, given the nature of psychosis, relapse is *likely*—even in an ideal environment. The guide also states that prescribed family therapy which intends to address EE does not decrease relapse (p. 86). Marshall et al. (2003) and Kaas, Lee, & Peitzman (2003) found that clinicians fail to normalize responses of family members to stress, fear, and behaviour changes they do not understand. Natural reactions to a mental health crisis do not represent longstanding family dynamics, yet are interpreted as such by proponents of theories of family causation. Marshall et al. (2003) express that intense stress is a common phenomenon inherent in all families at certain times, and thus does not necessarily represent “dysfunction”. In addition, even normal stress levels in families can trigger mental illness in someone who is vulnerable to it, so to blame families for illness or relapse is unjust.

Sjöblom, Pejler and Asplund (2005) found in their research with psychiatric nursing staff that, in their work, nurses identify a certain number of “problem families” in which the patient is seen as the victim of family pathology. They write that nurses tend to believe that even if the family wishes to be involved in the patient's care, it is preferable if the patient can “break loose” from them” (Pejler, 2001, cited in Sjöblom et al., 2005, p.567). A similar message can be found in the *Family Self Care and Recovery from Mental Illness* manual (Mood Disorders Association of BC, 2008), a tool designed to help families. When talking about promoting recovery, the manual suggests to families that despite their best intentions, their efforts to help their loved one will impede recovery. It is claimed that family members can easily become “enmeshed” with

their ill family member. If they do not “back off”, they will create problems for him/her (p. 34 & 57). Furthermore, the family will create unhealthy dependence, thus hindering their growth (p. 48). No documentation is provided to support these claims, and the authors write that they could not find literature on the topic. Other authors (Centre for Addiction and Mental Health, 2004; Nordby, Kjønsberg, & Hummelvoll, 2010) document the injustice of denying families the expertise they have in caring for their loved one, such as their ability to identify their child’s needs and to adapt their parenting approach to meet them. This expertise would automatically be assumed of parents in a different setting, such as on a regular medical ward in a hospital.

### **Predicaments Facing Families in Mental Health**

While the previous section reviewed literature which focused on the supposed toxic nature of families, this section examines research which documents the struggles of families in the mental health system. The current difficulty of families is attached to the era of deinstitutionalization, when patients were discharged from asylums such as Riverview Hospital in Coquitlam, B.C. (Davis, 2006). The expectation implicit in the act of sending patients who were still impaired into the community was that the family would take on the daily caregiving responsibilities for their loved one, supported by enhanced and adequate community facilities. Deinstitutionalization occurred without consulting these family members (Rowe, 2010; Wynaden & Orb, 2005). Currently families and other non-professionals provide the majority of care and support to people in the mental health system (Lakeman 2008). Consequences for caregivers include parents having by necessity to return to parenting roles for their adult child, and financial problems (Davis, 2006). For instance, parents may become unable to work because the caregiving burden is too heavy.

There are high expectations of families to make significant contributions to the lives of their loved oneloved one, yet their own needs are often met with little concern by professionals in the mental health system (Rowe, 2010) and they are not respected for their contributions (Kaas et al, 2003). Added to this lack of recognition are the additional thoughts and feelings of frustration, grief, doubt, guilt, exhaustion, depressive symptoms, and poorer emotional health (Centre for Addiction and Mental Health, 2004; Davis, 2006; Lakeman, 2008). There are also studies which indicate that there is even decreased physical health among these families who are the caregivers (Wynaden & Orb, 2005). Kaas et al.(2003) suggest that practitioner responses of blame or indifference towards family members add to the trauma of the families' experiences, and reinforce self-blaming thoughts.

Finally, clients' legal and ethical rights are upheld in the mental health system at the cost of caregiver rights (Rowe, 2010). For instance, the client has a right to privacy, but the caregiver arguably has a right to information about the care and needs of the person s/he is caring for each day in his/her own home. In the current system, according to Rowe, the former consistently takes precedence over the latter.

In general, families feel excluded by the mental health system (Clarke & Winsor, 2010; Kaas et al., 2003; Kirby & Keon, 2006). Doornbos (2002, cited in Sjöblom et al., 2005, p. 563) found that one third of families she studied could not find a single part of the mental health system that was helpful to them. This was echoed by Clarke and Winsor (2010) when the family members they studied, who were new to the system and had been interacting with psychiatric staff at the hospital, stated emphatically that health care providers had not been at all supportive of them (p. 245).

## **The Contributions of Families**

In general, treatment is greatly enhanced with family interventions (Chen, 2008; Marshall & Solomon, 2004a&b; Nordby et al., 2010), and family care is also cost-effective (Lakeman, 2008). In spite of their lack of recognition, it has been shown that families reduce the risk of mortality in their loved ones, decrease recovery times from mental illness and addictions, reduce relapse and rehospitalisation, improve medication compliance, and improve the clients' interpersonal functioning, including relationships with their families (Centre for Addiction and Mental Health, 2004).

Marshall and Solomon (2004a) document that in the United States, 75% of people with schizophrenia have ongoing contact with families to some degree, and 50-84% of adults with mental illness live with their families. Caregivers are usually the first to identify warning signs and symptoms of mental illness, yet with no formal role in the system, they are mostly unable to share these insights or help to intervene when their loved one needs it the most. The Mental Health Commission of Canada (MHCC) recognizes the important role of the family in caring for people with mental illness and promoting their well-being, and states that the potential for this should be the primary assumption (MHCC, 2009, p.61).

The recovery model in mental health, which has been in existence a relatively short time compared to the medical model, is being increasingly embraced by mental health services (Davis, 2006). Indeed, a BC Ministry of Health document refers to the recovery model as best-practice in rehabilitation (2002b). A principle of the recovery model is that mental health professionals encourage the development of a network of natural supports in the lives of their clients (Davis, 2006). Instead, clinicians typically work with the client in complete isolation. This practice fosters dependence on clinicians—paid staff who out of necessity maintain



personal and emotional distance by imposing professional boundaries—and is clearly less than ideal since they work nine-to-five and not on weekends. In contrast, caregivers are ready and willing supports, flexible in the nature of the support they can provide, and “on duty” twenty-four hours a day and seven days a week, yet their relationship with the client is neglected in treatment.

### **The Role of Research**

The contribution of research to mental health practice bears emphasis. Despite the climate of family mistrust that may exist, and despite a lack of acknowledgement of their important role of families in caregiving, those who espouse family involvement can readily find examples in the literature that are supportive of their practice.. If family involvement is an evidence-based best practice (Centre for Addiction and Mental Health, 2004; Marshall & Solomon, 2004a&b), educators may reasonably challenge the behaviours of mental health professionals, and call on them to change their practice accordingly. Gilgun (2005) writes of “falsification”, the duty of social workers to willingly seek information which challenges their previous understandings and to be open to research evidence which is contradictory. In the case of information-sharing, research consistently shows that collaboration with families in the community setting, which is indeed evidence-based best practice, is not occurring consistently, or is not occurring at all (Lakeman, 2008; Kaas et al., 2003; Marshall & Solomon, 2004a; Wynaden & Orb, 2005;). Marshall and Solomon (2004b) document that 85% of the clinicians they studied did not see the families of the majority of clients on their caseloads. Those who had seen family members in the previous six months had really only seen the families of a small number of their clients. Where there was family involvement it was mostly crisis-based and not

extended over a period of time. In times of crisis, information which was provided was still insufficient (Wynaden & Orb, 2005).

### **In the Name of Confidentiality**

Rules about disclosure to families in health care settings are inextricably linked to core values inherent in our health care systems and even our society. Chen (2008) documents the role that Western individualism plays in upholding personal privacy and self-determination when compared to collectivist societies. However, stigma plays a role in mental health. Families in the system are denied information which would aid them in their caregiving role—information they would otherwise receive as caregivers of someone with a physical condition (Kaas et al., 2003).

According to Wynaden and Orb (2005), maintaining a patient's confidentiality is seen as central to showing respect for the dignity of a person with mental illness. Furthermore, if clients fear a breach of trust, they may hold back information which would be vital to caring for them. However, these researchers qualify their statements by explaining that major mental illness affects judgement, reasoning, and understanding. In other words, clients who say “no” to information-sharing are not always able to apply the appropriate reason or judgment when doing so. This calls into question the appropriateness of honouring the client's wishes at all times. Davis (2006) notes that some clients may have negative feelings towards their family members (p. 87). This negativity in turn causes providers to be less likely to discuss family involvement or to ask for permission to release information to them (Bogart & Solomon, 2000). Davis points out, however, that clients may speak poorly of their family for a large number of reasons, including fictitious reasons and delusions (p. 87).

Chen (2008) notes that clinicians are often more than willing to gather information families, even without client consent, to use as they see fit. Yet, failure to share information reciprocally means that the family is unable to support treatment goals, ensure medication adherence, or promote recovery. Wynaden and Orb (2005) document that some clinicians, who defend confidentiality in the name of not jeopardizing the client's trust, will, at the same time, be quick to tell the client when his/her family calls the office, thus damaging the family member's trust with the client and even putting the family at risk.

### **Guidelines, Responsibilities of Clinicians, and Policies**

The British Columbia *Guide to the Mental Health Act* (2005) and the *Freedom of Information and Protection of Privacy Act (FOIPPA)* (1996) inform mental health practitioners about the laws which bind them. Legislation also tells practitioners that they can and should weigh the needs of the client against the need to maintain confidentiality. In some cases, then, professionals *can* disclose the client's personal information to caregivers without consent (FOIPPA 32.a & 33.c). This right is not solely for the purpose of preventing suicide or other serious harms. It may, in some circumstances, be exercised to enhance well-being or recovery (*Guide to the Mental Health Act, Appendix 13*). These acts suggest that disclosure should be considered on a case-by-case basis. This laws ratify documents which call family involvement best practices and evidenced-based (BC Ministry of Health, 2002a; Centre for Addiction and Mental Health, 2004), creating full justification for family involvement.

Indeed, the American Psychiatric Association guidelines, quoted in Marshall and Solomon (2004b), "recommend that psychiatrists educate families about their relatives' mental illness, early signs and symptoms of relapse, medications and side effects, and prognosis for the purpose of treatment planning and monitoring of functioning" (p. 215). The researchers add that

practice guidelines from other professional bodies recommend that families also receive “support, crisis intervention, and problem-solving skills” (p. 215). While the team needs to identify whom the bearer of this information will be to ensure that it gets done, these quotes illustrate information which is deemed appropriate to share with families by professional bodies in mental health practice.

Marshall and Solomon (2003) note that serious harm may come from inappropriate disclosure. Yet serious harm may also arise from inappropriately protecting information as well. Therefore, some disclosure is required for high quality mental health care.

### **Barriers to Collaboration**

The literature reveals that there are many barriers to collaboration. For instance, Kaas et al. (2003) state that practitioners have a “total lack of awareness” (p. 734) of the impact of mental illness on families and the burdens they carry, and that many see families either as benefits or liabilities, but not a group with their own unique needs.

**Pathologizing families.** Kaas et al. (2003) write that the family experience is truly a trauma-based response to a catastrophic event. Practitioners do not understand this, and interpret the resulting behaviour as dysfunction. These researchers argue that training manuals are steeped in a “pathology paradigm”, as opposed to identifying and seeking “coping, adaptation, and competence” in families (Mohr, Lafuze, & Mohr, 2000, as cited in Kaas et al., 2003, p. 744). As evidence for the latter, Reay-Young (2001) documented that families do adapt over time; they get over the shock, gradually learn to accept what has happened, and develop coping skills. The time this takes may vary, but it means that they require different kinds of support from the team over time, and also shows that their interactions with mental health professionals may transform over time due to these changing needs.

**Defining caregivers.** Another factor is that clinicians do not always understand to whom they can disclose. The Centre for Addiction and Mental Health (2004) clarifies that a caregiver includes kin, significant others, and those whom the client identifies as important to him. However, if these important people are not identified or known, a clinician willing to share information may nevertheless refuse to communicate with anyone except the client's parent. Dodge (2006) documents this in his research on the experience of sibling caregivers being excluded from contact with professionals.

**Knowledge of policies and procedures.** The nature of the confidentiality policies is also a barrier experienced by families, for several reasons. Clinicians have to know and understand the policies, and they have to competently apply the discretion found within them. Bogart and Solomon (2000) identify the lack of clear disclosure procedures and clear confidentiality guidelines as a significant barrier to family involvement. For instance, an American study on this topic showed that almost 100% of providers were conservative in their interpretation of confidentiality, and believed that they could not disclosure confidential information without client consent. However, over half did not know what information was, and was not, confidential. (Marshall & Solomon, 2003, p. 1622). In fact, the practitioners in this study interpreted "the law as being more restrictive than even the most conservative legal interpretation" (p.1626); they felt they needed consent to give families general information. This issue relates to a barrier which supersedes it, that of insufficient practitioner education (Kaas et al., 2003).

In addition, clinicians have to care enough about families and information-sharing to work with them. This requires beliefs about families as beneficial to the client's care and recovery, which have been shown to be lacking.

**Seeking consent.** An additional barrier is related to client consent as the main gateway for family involvement. Marshall and Solomon (2003) document that clinicians routinely fail to ask clients if they are comfortable with having their families involved. They may not initiate the question, or only ask once. They may ask when the client is sick instead of well, or in a way which does not engender agreement.

**Demographic variables.** Kaas et al. (2003) found that older professionals held different beliefs than younger professionals about barriers to collaboration with families; the former group felt more negative about the collaboration, causing the beliefs to be a barrier. However, Marshall et al. (2003) found that the number of years of experience of a practitioner was not related to their beliefs about family causation, in that both older and newer practitioners subscribe to family causation theories. When trying to understand why newer clinicians seemed to share family causation theories despite their more recent training, they reasoned that current training may not be dispelling family causation myths for newer professionals. Alternatively, more recent models such as “diathesis-stress” are being misinterpreted by these newer professionals. Marshall et al. also found educated, white, female providers were more likely to hold family causation beliefs, but that biological causation beliefs were not linked to a specific group. Both of these beliefs could be held simultaneously.

### **Strategies Previously Researched**

In this section, attempted interventions to increase information-sharing between professionals and family members are discussed. As well, the literature is examined, and reveals that attitudes towards families impact the success of the interventions used in the research.

Zipple, Spaniol, and Rogers published research about a practitioner training module in 1990, illustrating that while the issue remains, it has been recognized as a problem for some

time. The course designed by Zipple et al. (1990) was 18 hours long and taught by family members who belonged to the National Alliance on Mental Illness (NAMI). The research was effective in changing participant attitudes and increasing participant knowledge. However, only 55% of the practitioners completed the research instruments in entirety, and satisfaction regarding the training was only moderate.

Kaas et al. (2003) carried out research around a similar training program, one 10 weeks long and taught by a five member team consisting of a professional, two consumers, and two family members. Their conclusions were that ten weeks were insufficient to create substantial change, but that attitudes towards families were nonetheless improved to include increased compassion and an awareness of their challenges. This in turn affected the clinicians' practice.

Marshall and Solomon (1999) describe practices adopted by Riverside County in California and Allegheny County in Pennsylvania to address the issue of information-sharing. These practices include creating expectations of initiation on the part of practitioners, and the need to re-introduce the topic at preferable times. The practitioners created a consent form and guidelines for its use, information brochures for consumers and families, mandatory system-wide training, and specific procedures. An evaluation of effectiveness was never completed, but anecdotal evidence suggests high family satisfaction. Because of this outcome, the researchers provide recommendations to interested groups in their article.

Other strategies have met with moderate success. Marshall and Solomon (2004a) describe their study to evaluate the effectiveness of clarifying confidentiality policies with the use of a form and detailed training. They found the training to be helpful to clinicians but , in spite of the training, the form was not routinely introduced to clients in practice. They thought that the clinicians need to identify the value of the form if they are to implement it.

Lakeman (2008) documents the creation of practice standards to address poor levels of information-sharing. These were minimally successful and inconsistently applied in the community setting; similar to Marshall and Solomon's findings, Lakeman suggests that if attitudes around family involvement remain unchanged, practice standards will have minimal effect. However, both seem to be required for positive outcomes.

### **Ethical Considerations**

Capacity to disclose client information without consent was previously documented, but in social work this can be found in our codes of ethics. While the maintenance of client confidentiality is one of the "core social work values and principles" found in the Canadian Association of Social Workers' *Code of Ethics* (2005), acting in the client's best interest is the "primary professional obligation" in the *Code of the Ethics* of the BC Association of Social Workers (2003, italics added).

Rowe (2010), in a journal on nursing ethics, discusses the ethical side of practitioner decisions not to disclose to family members, and documents the unethical nature of expectations of caregivers in the mental health system. As mentioned earlier, parents, siblings, or other family members of adults with mental illness often lack the choice about whether to be caregivers. They also lack financial and emotional support for their role, respect, and often the information they need to do their role well. Their health tends to suffer, yet will be met with little recognition—even when basic empathy and support from clinicians could positively impact their health (Kaas et al., 2003). Throughout this time, their tremendous contribution to the life and well-being of their loved one is taken for granted, and may even be denigrated. Rowe (2010) uses a moral framework by Thiroux (2005, quoted in Rowe), to help nurses determine how "the value of life, goodness or rightness, justice or fairness, or justice, truth-telling or



honesty, and individual freedom” relate to the ethical dilemma of confidentiality in mental health (p.437).

### **Theoretical Framework**

In order to understand the perspective taken in the paper on the treatment of families, this theoretical framework will put forth two points for consideration. The first is a postmodern approach, focussing on essentialism and social constructionism. The second approach identifies a multi-layered system of oppression which unjustly impacts the treatment of families.

#### **A Postmodern Lens**

According to Baines (2007), postmodernism refers to the idea that what we perceive as “real” and “true” is actually a social construct. For example, concepts like gender roles, race, and disability have different meanings and are perceived differently from one culture or community of interest to another. In much of the Western world, the term “mentally ill” comes replete with images and connotations about “craziness” and “dangerousness”. Even though statistically those with mental illness are no more dangerous than the rest of the population (and are, in fact, more likely to be victimized themselves), they are nonetheless believed by many to be particularly dangerous (Schizophrenia Society of Canada, 2008). Dangerousness in this case is a “truth” which has been socially constructed, largely through news and entertainment media.

Essentialism is an idea related to social constructionism, whereby “natural, intrinsic, and unchanging” qualities or characteristics are attached to a person or group (Brown, 2007, p.132). Essentializing involves reducing these persons or groups to the sum of those “truths” which supposedly define them. Those with mental illness can therefore be collectively defined as inherently and naturally dangerous, bizarre, and unable to function—all to the same degree. In reality, of course, people with mental illness are actually unique in the ways that each individual

is affected by his or her illness, and even these differing degrees of impairment may vary over time. Because it is the result of widely held ideas in a community, essentialism contributes to inaccurate and often harmful generalizations about a group.

This paper is framed by the premise that families in the mental health system are essentialized not just by society, but by the mental health community in particular. For instance, in any given community, one can assume that most families are “typical”, and a small remainder could be quite difficult, dysfunctional, or unhealthy. Since mental illness does not discriminate, cutting across all communities and socio-economic groups, and since current research indicates that family dysfunction is not the cause of mental illness, it follows that mental illness will hit “typical” families and unhealthy families in the same proportion. Thus, of all families in a given catchment area of a mental health team, most will be “typical” and a small number will be unhealthy. However, it will be shown in the research that a number of clinicians ascribe an illogically high number of “problem” or “toxic” families to this population. Therefore, the perception by practitioners that the prevalence of dysfunctional families of clients in the mental health system is quite high can be identified as problematic itself, using the lens of essentialism.

This is not to imply that practitioners are without exception essentializing families, nor that the degree of essentializing is uniform throughout the mental health system. However, given the widespread difficulties described in the literature, it is fair to say that the problem is endemic. Even though many clinicians do have positive interactions with some families on their caseloads, this does not mean that they are free from this practice of essentializing families. If practitioners see the few cases that are working well for them as exceptional, essentializing is still occurring. Others may see the families with whom they work as individual and unique from each other, but may make generalizations about families outside of those with whom they work. Widespread

use of terms like “over-involved” or “toxic” to describe families or family members of mental health clients can pervade everyday speech between case managers and may occur in team meetings. There may be a shared “understanding” of what family work entails, which is implied in conversation by inflection, figures of speech, or body language. Therefore, even when family involvement takes place consistently, families may have been essentialized, and assumptions that follow may have been made before a family ever meets with a case manager. Arguably, these ideas which have permeated the minds of many clinicians will have an impact on the interactions and the experience of both parties.

Objectively, this “truth” about families is a social construction. It implies no ill intent, but rather the unconscious prejudgement of families, from which serious consequences may flow. To understand where ideas about families in mental health might have come from, it would be useful to recall the historical perception of families, which was far more overtly negative than what is occurring today. In the sense of postmodernism (Brown, 2007), facts and realities about families have been manufactured over time.

Given that, in my experience, many highly involved caregivers in mental health seem to be mothers, the social construct of mothering can be critically examined as well. Mothers in Western society are often essentialized and polarized as either “good” or “bad”. An example is provided by Van Acker (2005), who discusses a recent value-laden Australian government’s budget, which rewarded stay-at-home mothers while penalizing single mothers and mothers on welfare; she argues that this reflects ideas about good and bad mothers.

This construct of the mother lends itself easily to the mental health system. A mother may automatically be seen by clinicians as bad for having caused or contributed to her loved one’s illness and/or relapse. Alternatively, she may be a good mother until she is perceived as

over-involved; she then immediately becomes a bad mother. A mother may also be providing vital care to her child and thus is a good mother according to her friends and family, yet in a system which has claimed the right to define “appropriate” caregiving, she may be bad according to a clinician because her mothering is judged to be enmeshment. The mother could therefore simultaneously be a good mother *and* a bad mother. When mothers are essentialized, the richness of their mothering is denied and the differences between each are lost. When a woman becomes a bad mother, this will inevitably affect the interactions between herself and the mental health team.

### **A View of Oppression**

In her text *Justice and the Politics of Difference* (1990), Young writes that social injustice is created by oppressing and dominating societal groups. She suggests that oppressed people are unable to “develop and exercise their capacities and express their needs, thoughts and feelings” in their oppressive situation (p. 40). This constraint on capacities and expression of needs applies to families in mental health.

According to Young, there are five “faces” of oppression: violence, exploitation, cultural imperialism, marginalization, and powerlessness. Three of these are applicable, namely exploitation, marginalization, and powerlessness. The first is exploitation. That might seem extraordinary, but there is an imbalance when family involvement is invited at the convenience of clinicians, but disallowed when families seek it out. Families are undeniably helpful to the professional team because they have knowledge about their loved oneloved one which the staff could never glean in the space of a short time. Indeed, families likely wish that the team would ask them even *more* questions. Anxious to help and be involved, families are being included, yet only for the benefit of the staff. They are then shut out of participation when the staff do not

need them anymore, and do not get to ask their own questions which will help meet their *own* needs as caregivers. Therefore, families are exploited because practitioners use their privilege to extract “goods” in the form of information from families, while not compensating these families, who lack privilege, with much needed “goods” in return.

Families are also exploited financially, as it was documented that the closing of Riverview Hospital saved the government major funds; these savings were not used these to aid family caregivers provide this 24-hour care which the government would otherwise have paid for. Similarly, the lack of hospital beds can lead to potentially pre-mature discharges, meaning that the family is charged with a heavy care burden to solve the hospital’s bed crisis, care which can only be terrifying at times.

The very presence of families can be advantageous to the team. In their manual for families, the Mood Disorders Association (2008) quotes a parent describing how his/her family was being exploited as a convenient discharge plan. The manual uses the example to encourage families to stand up for their own needs. In this particular case, it was only the eventual refusal of the parents to take their daughter home which resulted in her receiving the care she needed; she merely required a practitioner to spend time finding her a more appropriate home.

However, families in general are frequently called to bring their children home, a strategy which is convenient and cost-effective to the mental health system. Reciprocation would include providing families with all of the information they need to be good caregivers (solely non-confidential information and that which is covered under continuity of care). Something is needed to balance this equation. However, Kjønsgberg, and Hummelvoll (2010) document many parents who fulfill their duty, yet feel petrified as they bring their child home because they have

been given no information whatsoever on what to do to help her. The relationship between families and caregivers can be unequal and exploitative.

The second type of oppression is marginalization, which Young suggests is the most dangerous. She explains that entire groups of people can be excluded from participation in a social activity, culture, or environment. In this case, families in general are being excluded from care planning and involvement in the treatment of their family member in the setting of the mental health system. She also writes that oppression “blocks the opportunity to exercise capacities in social defined and recognized ways” (p. 54), in this case, parenting. Respect is also lacking, so families experience the feeling of being unwanted and unappreciated. Milliken and Northcott (2003, as cited in Clarke & Winsor, 2010, p. 246) describe parents who “became disenfranchised as they realized the situation they were in was one where their experience and expertise as parents was marginalized.” Karp (2001) notes they are “kept in the dark [... and] disregarded” (p. 205).

Finally, the family suffers in its non-professional status, making it subject to another kind of oppressive experience, that of powerlessness; parents “lack the authority, status, and sense of self that professionals tend to have” (Young, 1990, p. 57). Added to this is a bewildering mental health system, fear, stress, trauma, and diagnoses many families have never known or at least never understood. This combines to create an imbalanced—and arguably abused—power relationship.

Notably, Young uses a newer definition of oppression, which she explains is changed from referring to a tyrannical power to being “everyday practices of a well-intentioned liberal society” (p. 41). This is important to understand, for it would be inaccurate to suggest that the psychiatric team is not well-intentioned, and also because oppression is being carried out not by

an “evil plan” but through simple, daily tasks and conversations of which most staff are likely unaware.

If the difficulty experienced by families is understood through these theoretical frameworks, the injustice of what is happening becomes quite clear. It is also possible to more readily identify how well-ingrained these ideas are in the mental health system, illustrating the challenge of addressing them. Arguably, these ideas and theoretical concepts are not recognized by many practitioners, however they provide a useful framework in which to understand mental health and mental illness, and the research results in this paper.

### **Ethical Considerations Noted in the Literature**

The research received University of the Fraser Valley (UFV) Research Ethics Board approval (see Appendix A). The research did not require ethics approval from Vancouver Coastal Health (VCH) Authority because the purpose of the study was for improvement of professional practice and did not require access to clients or to confidential information; under these circumstances it was deemed unnecessary by VCH. Subsequently the research plan changed, and an amendment was put forth to the ethics board. This amendment was approved.

### **Case Study Commentary**

As part of the education module, two case studies were handed out at the very end for discussion in small groups. This only occurred with the first two presentations, as the third presentation was terminated prematurely. Of the two case studies, only one was ever discussed, due to lack of time. Therefore, the same case study was discussed twice as a large group, and the second one not at all (see Appendix B for the case which was discussed).

The comments which came out of this case study showed that family-blaming notions may impact the practice of mental health professionals in ways of which they are unaware. This

was not an anticipated result of the case study discussion. Later in this paper the actual outcome of the research will be analyzed further, however, for ethical reasons all descriptive details of the group discussions during the case study were removed. Ethics approval and waivers were never obtained for formally gathering data during the training module. Unfortunately, an inability to cite the group discussions means that their content could not be included. The lack of detail unavoidably removes much of the power of those statements.

### **Providing Notes for Review**

Each interviewee was provided with the notes from his/her interview so that these could be reviewed. It was important that the participant's beliefs and perspectives be represented as accurately as possible. This was especially vital because the researcher recognized her own bias on the topic of family involvement, and did not want to inadvertently adjust interview data to suit a particular purpose. One participant in particular felt uncomfortable about her comments when she read them, because at one point she had apparently been joking or exaggerating but this was not evident in the researcher's notes. The words themselves, then, had been transcribed accurately, but the interviewee chose to make changes. In the end, all interviewees took ownership for their words through this process of review, reflection, and opportunity for revision.

## **Method**

### **Overview**

This research was an exploratory study which focussed on the impact of an education module. The module was designed and delivered to several community mental health teams as a vehicle through which changes in the perspectives of clinicians about information-sharing could take place. These changes could then be measured using two surveys, one carried out a week



prior to the workshop and another one month following it. The second questionnaire was later cast aside prior to use and replaced with qualitative interviews.

The researcher was recruited by Vancouver Community Mental Health Services (VCMHS) to carry out her research with them, as they sought a student for a research project with the focus on information-sharing in professional practice. There was a close collaborative relationship between the researcher and the VCMHS Coordinator of Family Support and Involvement (the VCMHS Coordinator). The Coordinator was instrumental in the arrangements and practicalities.

### **Instruments and Samples**

**Module.** The module was entitled “Families and information-sharing in the mental health system.” Three teams were randomly selected for participation from the eight adult mental health teams in Vancouver, except that one team was excluded because the manager could not afford the time, and another was excluded because it is unique in its high level of family involvement. The latter is a new initiative with a different mandate, and it was thought that presenting to this team could skew the results. The Coordinator spoke with the team managers beforehand and also explained the research purpose and plan to the case managers in their team meetings.

Prior to delivery, the presentation was screened by a group of women consisting of VCMHS managers and administrative staff. It was well-received. This screening also allowed the researcher to make changes based on suggestions from the group and allowed overall honing of the presentation. The module was then delivered to three mental health teams in Vancouver, mostly consisting of community case managers, and approximately 50 people participated in it.

**Questionnaire.** The pre-workshop survey, designed by the researcher, contained quantitative questions formulated to assess the beliefs, thoughts, feelings, and practices of clinicians around information-sharing with families (see Appendix C). It was composed of two demographic questions and 26 Likert scale questions, with an opportunity at the end for participants to make any comments they wished. The VCMHS Coordinator reviewed the questions as well as the Research Ethics Board. All workshop participants were part of the sample pool.

**Interviews.** Interviews had not been planned originally, but due to an impending inability to gather a sufficient number of post-workshop questionnaires, they were added to provide the researcher with more data. The interviews were semi-structured with 14 open-ended questions, and these questions were used as a guide (see Appendix D). The interviews were designed to qualitatively explore and assess clinicians' perspectives on the education module and what they learned. In addition, the researcher also sought a higher level of detail about clinicians' beliefs, thoughts, and practices around information-sharing with families than the questionnaires could provide. This information was sought because it could prove integral to the development of future workshops on the topic, which would be undertaken by VCMHS. The schedule of questions, designed by the researcher, was approved by the VCMHS Coordinator as well as reviewed by the UFV Research Ethics Board.

### **Data Collection**

**Module development.** The researcher drew on a number of sources when creating the module. This included suggestions from the information-sharing interventions in Marshall and Solomon's (1999) article, which described their own successes and learning points. These suggestions encouraged the researcher in her decision to include detailed handouts, for instance.

The researcher was also supported by the VCMHS Coordinator in locating relevant policies which could be found in the *Freedom of Information and Protection of Privacy Act* (FOIPPA) and the *Mental Health Act*. When collecting data, she met with the Early Psychosis Intervention (EPI) team manager, which was valuable because of EPI's unique mandate to involve family members to a high degree. She also met with VCMHS' Family Advisory Committee (FAC). In addition, exposure to the stories of families in the mental health system was viewed by the researcher as a powerful learning tool, and therefore part of the module development involved asking the VCMHS Coordinator to gather stories from various family members in order to better illustrate her points during the workshop. It was important to the training and to the research framework that families, who were considered voiceless, be given a voice. These stories were a means through which the families could be present in the training. Direct quotes were inserted into the Power Point presentation, and the researcher elaborated on them in the module. Some of the quotes will be mentioned here in order to illustrate their value to clinicians who are receptive to the lessons inherent in them.

**Stories for the module.** The following five stories, merely snapshots in time of extended periods of struggle, illustrate the challenges faced by families. They also represent the experiences of many other family members.

One parent describes calling her daughter Lisa's<sup>2</sup> private psychiatrist to tell him that Lisa had attempted suicide. She knew Lisa would be angry, but felt the information was important. Instead of being thanked, she was charged by the psychiatrist with interfering and told to stay away. She writes of "feeling numb, alone, ashamed, as if I had done something wrong, [and] silenced." Lisa's mother has given up on ever being involved in her daughter's treatment "even from a distance, although I have bought her groceries, paid her rent, talked to her late into the

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<sup>2</sup> Names and indentifying information changed to protect anonymity.

night and have taken her to the hospital early in the morning.” This experience of being silenced shows that valid attempts to contact a mental health professional can be rejected, devastating a family member. Furthermore, an extension of families needing detailed information about their loved one to properly care for them is that excluding families from treatment planning is also detrimental to recovery. Families cannot help support recovery goals which are identified by the team if they do not know what they are. This could include, for example, promoting healthy sleeping habits, helping their relative have a more structured day and attend recreational activities, driving them to appointments at the team, or assisting with medication management.

A different story about family involvement comes from the brother of Jenny. Jenny announced to him one day that her team said she was much improved and she no longer needed to attend. He knew full well that she was still quite impaired; a team who thought they understood Jenny had better ask someone who knew her. Alternatively, he questioned whether her statement was factual, but he had no way of finding that out. He only wanted basic information. He wanted to support Jenny in her treatment goals to improve her life, and she had never expressed unwillingness to have him involved. He was “just” a sibling to the team, but he was the only caregiver Jenny had left.

In another case, Jeff, who lacks complete insight about his illness, does not want his family to participate in his care. His mother writes that if Jeff has to be forcibly confined to a secure psychiatric unit because his judgment suffers and he is deemed incapable of taking care of himself, “it’s open to serious question as to whether or not you have the facility to order a senior physician not to talk to your family.” Notably, Jeff’s mother is referring only to information-sharing permissible under continuity of care.

One mother writes: “I’ve long learned that most professionals, from the social worker to the physicians, really don’t have useful advice as to how to deal on a practical level with our loved ones.” Her message is that while most clinicians know how to spend half an hour with a psychotic client on a weekly basis, they have never tried to live with someone that sick. This is not to denigrate skilled practitioners, but to suggest that most cannot appreciate the daily struggle, a struggle seemingly neither acknowledged nor valued for the contribution that it is. Additionally, if the team is unable to meet their needs for reasons such as time constraints, parents need to be offered resources and other sources of support which will help them cope.

In a letter of complaint to a team (offered to the researcher as data), a mother expresses that “as parents [...] we are well aware that without [...] mandated medication, Tom [...]—who has strong symptoms of anosognosia—will slide into severe psychosis yet again. Along with psychosis [...] will come issues of near starvation and verbal threats to cause harm to us and our property [...]. However, what is most distressing is [...] the lack of any attempt to contact family members for consultation.” Here the family is a source of insight, yet their input is not being sought out, with potentially frightening consequences. Given anosognosia (lack of insight into one’s illness) and a history of going off medications, Tom’s relapse will be forthcoming if he is not forced to take any. While the well-being of Tom’s case manager will not be affected by such a decision, the well-being of the whole family stands to change drastically. The mother has accepted this, but she wants her perspective as a parent to be valued.

Notably, the stories are not all bad. One mother expresses extreme gratitude for the interventions of her daughter Ella’s case manager. She phoned Ella while on vacation and did not hear back—an abnormality for Ella. Far from home, she got scared. Once contacted, the case manager looked for Ella, found her unwell, and took immediate action. The mother feels

that her promptness prevented a hospitalization and saved the whole family much trauma. While some families have good experiences, the ease with which the unfortunate ones can be procured is troubling.

**Using quotations in the module.** Another tool used in the presentation was a collection of quotes which had been gathered from a chapter in a guide designed to help families involved in the mental health system, created by the Mood Disorders Association of BC. These sentences were combined into a stand-alone paragraph and read to the participants. The quotes inform parents of adults with mental illness that, despite their good and loving intentions, they have no expertise in caring for their own child and knowing how to foster his growth as he recovers. Instead, they will, if left to their own devices, stunt his development at the very point when he needs most to grow and gain independence. This paragraph can be viewed in Appendix E. What is noteworthy is that the authors qualify their claims by stating that they could find no evidence to support them. In other words, the statements are based on ideas about families with ill loved ones as opposed to evidence. In the workshop, the researcher asked the participants if they could identify the overall message and what was implied if there was no research to support it. Case studies were also created, drawing on real stories submitted to the VCMHS Coordinator by family members.

In terms of data gathered at the presentations themselves, the researcher did not seek ethics approval to formally collect data during those training times, but notes were taken which contained anecdotes from the presentations. These notes did not contain confidential or identifying information.

**Questionnaire.** The researcher posted the pre-workshop questionnaire on Survey Monkey. Prior to the workshop, the participants self-selected by clicking on a link to the survey

which was found within an email sent to all team members from the VCMHS Coordinator. As the information letter was attached to the email as well, consent to the research was implied by the participant filling out and completing the survey.

Notably, an unforeseen delay in ethics approval may have impacted the completion rate. As the workshop dates had already been set prior to receiving approval, the delay meant that the email with the link to the survey had to be sent later than intended, and thus some participants had less than a week to carry out the survey. This timing issue was mentioned anecdotally by several workshop participants when they arrived for one of the presentations, but participation was poor in general even when timeliness was not a factor. This can be understood in part by the work commitments of the participants, although other factors could have been disinterest or ambivalence around the topic of families or the fact that it was a student project. The design assumption and limitation in the research was that it relied on enough case managers taking the initiative to fill out the survey *prior* to the module that a minimum of 25 *final* questionnaires could be completed. Due to attrition which would occur for a variety of reasons, many more than 25 initial questionnaires would have needed to be filled out. In the case of this research, a further complication was that a large number of participants abandoned the third workshop half way through the presentation. Clinicians could not fairly be assessed for learning if they were not in attendance when the material was presented, as this would skew the results.

Through the use of Survey Monkey, 25 practitioners completed questionnaires. This accomplishment was facilitated by the manager from the third team. Only 15 surveys had been completed up to that point out of approximately 30 participants from the other teams, and at least 25 were needed to reasonably analyze the data. After the researcher arrived, considering that so few questionnaires had been completed by all three teams up to that point, the manager asked

most of the participants to complete the questionnaire prior to the start of the workshop. In total, 25 were gathered.

It should be noted that when analyzing the results from Survey Monkey, which was available in graphs, the researcher found a high number of neutral responses. Hodge and Gillespie (2003), in their analysis of the drawbacks of five-point Likert scales, explain that “neutral” (the mid-point) is often considered by observers to represent a value which lies in between agreement and disagreement. However, it is often selected by participants when they simply do not know the answer, are undecided, or find it inapplicable to them. In this case, it could be speculated that selecting “neutral” might also be a response to discomfort being experienced around a question, particularly if the participant associates a value judgment with the other responses.

Ryan (1980) discusses how statistical significance is affected by the mid-point. Given the small sample of questionnaires, this was particularly relevant. Ryan further discusses that the mid-point can be available as an option to participants but then removed for analysis, which was done for this research. Furthermore, again due to sample size, scale items were merged. The researcher combined the answers of those who “agreed” and those who “strongly agreed”, creating a single affirmative category. This served to create a higher contrast between those who responded positively and those who responded in the negative.

**Interviews.** The VCMHS Coordinator employed convenience sampling to provide the researcher with a small number of practitioners who were willing to be interviewed. Once they agreed to participate after being approached, the VCMHS Coordinator provided the researcher with an email address and/or a work telephone number for each. In total, five interviews were carried out, each lasting 30-45 minutes. Four interviews took place by telephone and one was



conducted in person in the participant's office. In order to be eligible, these practitioners had to have attended the module. Prior to posing questions, the researcher reviewed the informed consent letter with the interviewee. The interviewees were encouraged to share their views about the module, both positive and negative, without needing to have concern for the feelings of the researcher. This was done because the researcher had developed and presented the module. It was therefore clarified that interviewees should speak honestly and freely without fear of "wounding" the researcher.

### **Data Analysis**

**Module data.** Anecdotal data in the form of comments made to the interviewee during or after the module were compiled. Only comments which were useful to analysis, however, were noted down and these were few in number. These comments were compared and contrasted to themes which were identified in the questionnaire and the interviews. Other anecdotal data included outcomes from the case study, which two separate groups analyzed in different yet unexpected ways. These were then used to document perspectives on families.

**Questionnaires.** Survey Monkey's software allows for very basic analysis of data. For each question a simple bar graph is displayed, along with the percentage of responses to each Likert scale item. The themes found within the questionnaire were manually grouped. The theme categories included: "responses favouring families and family involvement," "perspectives and challenges around family involvement," and "perception of role and appropriate practice".

**Interviews.** Notes taken during the interviews were typed up right after each interview, and made into separate documents. The data was first formally analyzed after four interviews had taken place, as this was required for an assignment which was due before the fifth interview

had occurred. The data was being processed from the beginning of the research and was an ongoing process. As each interview took place, ideas raised by the participant were added to previous ones and compared and contrasted, in a recursive process. This process was facilitated by having ideas as to which themes might arise, although the process did not preclude identifying emerging themes. By the fifth interview, the researcher was asking those questions which were yielding the most interesting and relevant information—the interview process was developmental and evolving. As themes emerged, data from the interviews were transferred into a different document which was separated into distinct themes. These themes included family blaming, perspectives on disclosure, perspectives on family involvement, and negative reactions to the workshop.

### **Findings**

This section will provide an analysis of data which was collected formally in the questionnaire and the interviews, as well as anecdotal data gathered from the module. It will be revealed that some of this data is complex and not in agreement, which serves to highlight differing perspectives as well as illustrate existing tensions and contradictions. These incongruities may exist within a team, such as co-workers having differences in beliefs and practices, or may exist within individual clinicians themselves. In this section, the module will be discussed last so that the outcomes can be considered in light of the more formal data. However, anecdotal comments from participants during and after the module will be grouped with the interview data; most are individual and unrelated, but they do lend strength to the formal data when the two are combined.

## Questionnaire

The questionnaire provided the first source of raw data. It served to document both positive and negative perspectives about families and information-sharing. As noted in the method, the mid-point was removed from the scale during analysis, and scale items were combined to provide higher contrast to the data. In this section, the term “respondent” is used to indicate participants who answered a question either in the affirmative or in the negative, as opposed to selecting the neutral response.

**Demographics.** The 25 questionnaire participants included psychiatric nurses, social workers, clinical counsellors, occupational therapists, a psychiatrist, and non-specified “others”, many of which may have been registered nurses (RN). RNs were not listed as a category on the survey, as the researcher did not know they were employed as case managers and never discovered this during the planning. Psychiatric nurses, completing eight of the 25 completed questionnaires, were most highly represented, and seven participants qualified themselves as “other/prefer not to specify”. This leaves four occupational categories, each with little representation, so profession-based comparisons have not been made.

Eight of the practitioners were new to the field, with 1 to 3 years of experience, and five participants had 4 to 6 years of experience. Five had 7 to 10 years of experience, with the remaining seven having over 10 years of experience. From the researcher’s perspective, newer practitioners can be seen to lack experience, yet they have the benefit of more recent training and education. The latter is potentially relevant to beliefs about family causation.

**Data.** The neutral response was selected to a great degree, as previously discussed, and in fact it received the highest percentage of responses in seven of 27 questions. This could indicate discomfort with the questions, as some of them, using language which may be known as

“taboo”, asked about interpretations of families. Forty-four percent of the respondents, for instance, did not provide an opinion on whether or not families are often “over-involved” and cause problems as a result.

***Responses favouring families and family involvement.*** The table below summarizes the responses to attitudinal questions about family involvement and working with families.

Table 1: Attitudes regarding family involvement

<b>Responses favouring families and family involvement</b>	Responses	Total N
I see value in working with families, as they have a lot to offer us.	25	25
I work with families on a regular basis, with positive outcomes.	16	19
Lately I have been thinking about working with families more than I have in the past.	4	7
<b>Responses not favouring families and family involvement</b>		
It seems as though the families of my clients are frequently over-involved in caring for them, causing problems for my clients.	1	14
It is often in the best interest of the client that I do ‘not’ interact with his/her family.	2	16
Involvement with families should be limited.	3	16
I hesitate to be in contact with families because they can be a major contributor to my clients’ instability.	0	16
“Toxic” or “problem” families are a common occurrence in our work.	8	16

When considering most of these questions in isolation, clinicians seem to feel quite positively about families and their contributions. They seem to work regularly with them and experience good outcomes. However, the last question suggests the existence of more negative views of families which would otherwise not have been apparent. Note that the first two questions, answered so positively, can be seen as superficial in nature.

***Perspectives and challenges around family involvement.*** The following table examines perspectives attached to direct practice with families.

Table 2: Challenges to working with families

<b>Responses showing struggle around working with families</b>	Responses	Total N
Sometimes it is easier not to work with families.	11	17
Thinking that I want to (or I should) increase my work with families is one thing, but actually doing so feels a bit overwhelming.	12	19
Working with families is easier said than done.	13	18
I worry about losing the trust of my client if I talk to his/her family.	6	13
I feel “stuck in the middle” when I interact both with clients and their families.	2	11
It would be easier to work with families if the rules on when and how to involve them were more clear.	13	13
Applying discretion in my practice is the hardest part of information-sharing with families.	13	18
Applying confidentiality guidelines is so tough because each case is uniquely challenging.	18	21
Sometimes I worry that by speaking to families I will break confidentiality and get in trouble / be reprimanded.	9	18
I struggle with knowing when I am, or am not, allowed to talk with clients’ families.	9	18
<b>Response showing confidence around working with families</b>		
I have the tools I need to work with families.	8	16

This table shows that some staff find family involvement easier than others, but it seems to be seen as challenging by everyone to some degree. For a portion of this group, work with families can actually be fraught with fear and/or worry at times. Others would merely appreciate more tools or information which could provide more clarity on the subject.

***Perception of role and appropriate practice.*** The table below summarizes clinicians’ responses to questions about policies and responsibilities.

Table 3: Knowledge or beliefs related to policies and responsibilities

<b>Responses showing inaccurate beliefs about policies/responsibilities</b>	Responses	Total N
I have to maintain the confidentiality of my client at all times unless suicide or homicide is imminent.	14	18
When we talk about a client being at risk for harm (or being in need of protection), we are basically talking about suicide or other forms of death/major injury.	10	22
Case managers working at the EPI Program are allowed to work with families because their clients are under age; as our policies are different in adult mental health, I cannot practice with families in the same way they do at EPI.	5	15
<b>Responses which show understanding of policies/responsibilities (or belief that policies are understood)</b>		
VCH policies allow, and even encourage, me to work with families.	16	17
The family of my client is also my client.	11	19
I feel confident applying the concept of “continuity of care” in order to work with the families of clients towards care plans or case management.	14	18

Some of these answers show that important policies are misunderstood, which may be negatively impacting clients and families in the community. This is also true for the last question about continuity of care, for it will be seen that confidence that one knows a policy does not rule out being mistaken. Clinical perceptions or misperceptions regarding roles and duties towards families indicate the value of providing clinicians with detailed guidelines.

***Additional comments.*** Two participants expressed in detail at the end of the questionnaire that lack of time to carry out family work is the major barrier to doing so. One

expressed that as the client is the priority, family involvement comes second and therefore suffers. The other wrote that it is a wholly unrealistic expectation on the part of management that case managers add a new duty to an already full load, and particularly so because staff are insufficiently trained or educated to work with families.

## **Interviews**

Five interviews with community mental health case managers were conducted. These interviews took place between three weeks to three months after the module was delivered. The interviewees were cooperative, seemed interested in participating, and expressed their opinions in detail.

**Demographics.** Interviews were completed with a clinical counsellor, a registered nurse, a social worker, an occupational therapist, and a psychiatric nurse, all acting as case managers. This consisted of one male and four females. All had been practicing for over 15 years, save one, who had less than 5 years experience. No other demographic data were gathered. This limited demographic data collection was purposeful, as the researcher did not have the intention of drawing conclusions based on other participant characteristics with this small sample. Each interview took approximately 30 to 45 minutes to complete. After the interviews, the participants were sent a summary of their interviews and were given time to reflect on the content. In general, only a few minor changes were requested by the interviewees.

**Qualitative Themes.** A number of themes were generated in the data analysis. The discussion of themes includes: a perceived lack of time for professional development opportunities, reactions to the workshop, disclosure, participant perspectives on family involvement, and social work perspectives on families.

***Lack of time and resources.*** The lack of time mentioned by those who filled out the comment section of the questionnaire was also identified as a challenge by the interviewees. The issue of time referred mainly to lack of clinical time to work with families. None of the interviewees suggested that the inclusion of families might not necessarily be additive to one's time, nor that time spent with the family could potentially decrease the overall case management needs for the client. Lack of time was also discussed with regards to education sessions and training. One participant suggested that clinicians cannot spare more than 30 minutes at a time for training, while another stated that anything over an hour is too long and that there is a diminished capacity to take in new information after an hour.

***Negative reactions to the workshop.*** It was generally felt that the workshop was too basic. Three participants said that it failed to provide sufficient depth on the complexity of family involvement. The teaching method was also perceived as ineffective because it was a seminar style of learning; four of the interviewees said that they learn best in a more clinical training which consists mainly of case studies and large group discussion. Those participants who were concerned about their lack of time expressed that too much time had been spent on certain topics, and background information should be relegated to handouts to save time. Another participant reflected on the challenge of taking questions from participants when a workshop is quite information-heavy, as there is not enough time for good discussions which could result from questions. Finally, one participant stated that s/he left the workshop more confused about disclosure than before s/he attended the workshop. As disclosure policies involve discretion, learning about their "grey areas" did not make the topic clearer. S/he also referred to the existence of mixed messages between the presentation and how s/he has been instructed to practice at her team.



***Positive reactions to the workshop.*** Three of the interviewees suggested that the workshop had been of great value around two areas related to disclosure. Firstly, it was helpful when the concept of continuity of care as it relates to families was defined and clarified. This workshop feature resulted in clinicians feeling they understood the concept better, since it was previously not understood in its entirety. This was also mentioned anecdotally by participants in the module.

Secondly, it was also helpful to interviewees when the *Mental Health Act* and the *Freedom of Information and Protection Act (FOIPPA)* were clarified in detail to illustrate ways in which families can be included, and when information can be disclosed to them.

The information was not new to all participants, but for some it served to point out the “grey areas” inherent in the issue; this created a helpful contrast against the alternative: a “black or white” model which rejects family involvement outright. One interviewee looked back on a previous case with the realization that s/he could have handled it differently, for s/he had been more strict regarding disclosure than was necessary. It became his/her intention to reconsider his/her practice and discuss the situation with the family member anew. Related to this, two participants suggested that the workshop content on disclosure policies did not change their practice, but gave them comfort that these policies would support their clinical decisions.

***Perspectives on disclosure.*** One participant, explaining a personal approach to disclosure, referred to the workshop, where it was stressed that clinicians should meticulously document all details surrounding a disclosure. S/he stated that s/he has always done so very carefully, because it “backs me up.” Two clinicians expressed having no difficulties disclosing to families when it was appropriate. Notably, these two were those who found value in the workshop. However, even though they disclose quite comfortably when it will benefit the client,

they both made reference to a small yet ‘nagging’ fear that something would go wrong and they could ‘get in trouble’. These clinicians do their best to have their clients’ permission around disclosure. If the client says no, they keep trying to obtain it by re-framing the question. The practitioners try to help the client see family involvement as valuable to their recovery instead of an intrusion of privacy. If the client continues to say no, these clinicians will examine the case to decide if the “need to know” outweighs the client’s wishes, and are quite willing to disclose without consent as necessary. These interviewees thought that each client is different and any potential disclosures need to be considered in light of the client’s unique situation—as opposed to seeing disclosure from a “black or white” perspective.

Other participants stated that they will disclose if it is a necessity, but they do their best to avoid it, as the rights and privacy of the client are paramount. This is precisely how they were trained. Receiving information about clients from family members is quite acceptable to them, however. This is especially true if it is offered to them, as opposed to them calling the family to elicit the information.

In general, concepts like transparency and therapeutic rapport in the client-therapist relationship were important for all interviewees. For the first two participants, these concepts were general goals and ways of practicing, but for the other three, transparency had to be maintained at all costs in order to preserve the therapeutic rapport, and families would be excluded if the client showed any resistance. Sharing information without consent was not optional, and if the client said ‘no’ to these practitioners, it ended there—there were no questions asked.

***Perspectives of family involvement.*** Two interviewees identified the benefits of family involvement. One participant stated that family is incredibly helpful and important for client

care, and that openness and respect is key when working with them. Another said that the team, the client, and the family all benefit from family involvement. He/she also stated that case managers would have to “pick up a lot of slack” if families were not there to help their loved ones. One of these participants had previously worked in an environment which mandated family involvement, which was correlated to his/her current beliefs.

The rest of the participants were more neutral on the topic; sometimes it was helpful, sometimes not very helpful. One could not make general statements about the benefit of family involvement. For the remaining three participants, family involvement was not upheld as something to strive towards or something that tended to be beneficial to them or their client as a rule. Family involvement, on the whole, was not perceived as something that needed to be increased in their practices.

***Family-blaming.*** Several interviewees recognized that family-blaming was a systemic issue in the past. However, they felt that the problem had improved, and suggested that family-blaming is not particularly problematic in mental health today. They suggested that family-blaming is a practice that could “die out” as more experienced clinicians retire, which implies that older practitioners blame families but younger ones do not. Practitioners also stated that having an awareness of the existence of family-blaming meant that it had less impact on their own practice; emphasis on self-reflection in their professions leads them to automatically challenge themselves if they do engage in family-blaming. Therefore, even if they are “guilty” of family-blaming, it has little influence on the families with whom they work. For instance, they would maintain contact with a family despite experiencing irritation with them. Participants also expressed that if clients speak negatively towards their families, there usually is a reason. Since sometimes these reasons include serious issues such as abuse, clients should

never be pressed to involve their family members in treatment. Because of this potential history of abuse, the clients' reasons for refusing permission do not necessarily need to be explored or assessed for validity.

One participant expressed s/he has seen little evidence of family-blaming at his/her team, but s/he knew that it existed. Mainly, families s/he had known in a setting more inclusive of families had expressed to him/her that they had become disillusioned about adult community mental health services and felt excluded from them. In the mind of this interviewee, the families' negative experiences were related to family-blaming. Yet another participant said that from her perspective families are truly not allies in the system, and are can be blamed for interfering in treatment or for problems such as non-compliance. One participant suggested that clinicians may anticipate an angry reaction from a family member without justification, indicating pre-conceived notions about that family.

***Family behaviour and involvement.*** One participant identified that family behaviour can be interpreted negatively as over-involvement. However s/he suggested that behaviour can also be re-framed for different outcomes. Instead of avoiding or denigrating a family, the clinician can work with them to help them learn skills which will be more helpful to their loved one. This can lead to a number of positive outcomes for everyone involved.

One participant expressed that s/he senses palpable resistance amongst his/her colleagues when it is suggested that they should do more work with families over and above what they do already. This participant suggested that her colleagues think that they already, and currently, work with families a significant amount of time. Furthermore, it was suggested that resentment is experienced when management brings up the topic.

***Factors affecting practice.*** In this research, having many years of practice was not an indicator of either positive or negative beliefs about the family. There is conflicting evidence in the literature as to whether age or years of practice impact family causation beliefs and willingness to work with families. In the interviews, four participants had over 15 years of practice. Two of them identified the benefits of family involvement and disclosed as need be in their practice, whereas the other two did not identify a great deal of benefit and avoided disclosing as much as possible. The younger clinician agreed with the latter two and did not feel comfortable with disclosure.

Attitudes about families may also be affected by the theory and the theoretical framework used in practice. The social worker who was interviewed thought that concepts in social work, such as family systems theory, may help him/her understand the value of families more than her colleagues from other professions. This worker's comments suggest that some co-workers may "tolerate" family involvement as opposed to openly inviting it. Another social worker, who attended one of the module presentations, made a similar comment.

## **Module**

Data from the module itself, in the form of the researcher's observations of participants during the workshop, add perspective to the analyses of the questionnaire and interviews. This data is unique because it does not merely document that which clinicians express about themselves and their practice; it shows—through their actions—what they may believe. Mainly, it suggests evidence of family-blaming, and also illustrates frustrations which seem to exist around expectations that clinicians work with families.

The paragraph of family-blaming quotes located within a guide for family members (discussed in data collection and provided in Appendix D), was identified by one participant as a

modern day double-bind, whereby the parents do harm and are faulted if they do *not* help their child, but also do harm and are faulted if they *do* help their child. One other participant nodded his head, demonstrating that he found ‘fault’ with the paragraph, but most did not express an opinion, sitting silent and still. A few comments illustrated the belief that the quotes reflected reality.

The case study, designed as a tool for group work, asked module participants to examine how family involvement could a) be enhanced, and b) create better outcomes for a client in a given situation. The participants made an effort to address these questions. However, there was a tendency to dismiss the questions, such as by deciding that family involvement was already occurring and thus no more was required. Instead, they discussed other issues to be found within the case study. Interestingly the family in the case seemed to be interpreted as problematic for the client. The scenario provided in the module was based on a real case where family involvement was enhanced by the clinician and her manager (beyond the data provided to the participants), and the client, the family, and the team benefitted from it. The case study is provided in Appendix E. However, the comments which were made cannot be provided for reasons which have previously been explained

In the third module, the participants all but left the session before it was over, which is the main reason that the second questionnaire was cancelled and interviews were used instead—not enough data could be gathered within the available time frame. The reasons for these departures were varied, and may have included a misunderstanding as to the length of the presentation. However, when the entire class exits during a presentation on a delicate subject, it is possible and important to interpret the meaning of empty chairs. In this case, the emptying of

the room appears related to the topic and/or how the message was being perceived in the presentation.

It is likely that members of this team feel sensitive about the suggestion that they work more with families. The clinicians, in all probability, took this very message from the module. Although the actual message of the researcher was somewhat different, if clinicians felt that their significant efforts and family involvement were not being acknowledged, this could explain why they left. Among other things, it was discussed with the manager after the meeting that a “heads up” would be useful to the next presenter, as the manager had previously identified this issue. The VCMHS Coordinator later gave the researcher informal feedback from the team, which was that the content was engaging and the handouts were useful.

### **Implications for Practice and Policy**

This research examined the practices and perspectives of clinicians with regard to families and confidentiality. In the questionnaire, participants expressed positive beliefs around families and family involvement. However, the other answers showed mixed ideas about families and family involvement, and illustrated that clinicians struggle to include them.

The interviews identified two types of practitioners amidst the five interviewees. Although this is a simplification, one group of practitioners sees value in involving families and appropriately applies disclosure policies in order to do so. The other group of practitioners does not identify family involvement as generally beneficial and strictly avoids disclosure whenever possible. The first group works readily with families, and the results are visibly beneficial to themselves, the family, and the client. The second group does not work with families as a rule. When they are compelled to do so, they do not identify it as beneficial. This discrepancy in family-involvement and accompanying beliefs documents the interplay between positive ideas

about families in mental health and a practitioner's involvement with them, perhaps also representing a self-fulfilling prophecy. Similarly, positive outcomes of working with families may be connected to a positive family orientation as a starting place. These conclusions are fully supported by other research in this area. In the literature review, interventions such as creating practice guidelines proved ineffective if perspectives of families were not addressed. The attitude to families is the key factor in a clinician's willingness to use such tools, and thus beliefs about families need to be targeted before anything else. For instance, in the questionnaire, almost all participants identified knowledge of VCH policies which support and even encourage family involvement, yet this is not evidenced in practice. Their beliefs about families may be impeding application of this practice.

An awareness of the relationship between attitude, practice, and even outcomes allows for more effective interventions in the future. In order to increase the chance of success, it would be desirable to incorporate the feedback from the participants. This opportunity to understand their preferred learning styles and their needs allows another presenter the capacity to enhance the engagement of clinicians, for better outcomes. The researcher has since discovered that a seminar-based format, two hours in length or more, is indeed the main presentation style used for workshops in VCMHS. Yet if a different method is ideal or preferred, this can easily be accommodated. Notably, information about families was perceived by some as "basic" while information on policy was appreciated. Given the literature, it is more important that the former be fully grasped than the latter, or at least prior to the latter. Therefore, it would be essential to provide information about families in a way which is more compelling.

In general, failure to apply information-sharing policy appropriately seems to be related, at least in part, to misconceptions about the role of the family as a causative agent in their loved



ones' illnesses. Family-blaming and insufficient family involvement is impacting families and clients negatively, and is not justifiable given the amount of evidence which exists about families and family involvement as important to the lives of clients in the mental health system.

Therefore, while information-sharing policies may remain unchanged, health authorities and mental health programs or teams could be more proactive and persistent in ensuring that the policies are followed. Health authorities could do more to make sure that families or other caregivers are involved in the treatment of clients.

Facilitating a paradigm shift around what constitutes family involvement may be an area of focus in practice. In the interviews, it was commonly suggested that family involvement does not in fact need to occur more often, as case managers are actively involving families in their practice now. Yet concerns about family involvement on the part of families in Vancouver have been well-documented, and VCMHS administration also identifies that something needs to change. This is a clash of perspectives which may lead some practitioners to be frustrated by these newer expectations of them. Therefore, the goal might be to go beyond increasing the frequency of family involvement to altering the nature and quality of those interactions.

Referring back to the theoretical framework, many clinicians may be impacted by the way that families in mental health have been essentialized. For instance, if families of mental health clients are seen as inherently disordered, the approach of the case manager when interacting with a family may be one of wariness. Similarly, if "realities" about these families have been socially constructed (which is notable because this construction is not society-wide, existing only within the mental health system), seeing family members as "toxic" or "over-involved" participants unavoidably affects the interaction. Therefore, if beliefs and attitudes about families changed, the interactions themselves could take on a different nature and quality.

The contestation around frequency loses relevance because of the value attached to a quality interaction when compared to unpleasant ones.

In terms of professional development, there was a common interest amongst participants in receiving more clarity regarding appropriate disclosure to families, and particularly for a workshop which will examine information-sharing in greater depth. There is a readiness from practitioners for more, and they seem open to learning, which can be used to full advantage. It was also suggested that clinicians need recognition for their efforts to work with families and to be shown how to enhance this, as opposed to feeling that their hard work is being denied. Similarly, preferred learning styles were identified, so future educators can use such tools to increase engagement. These, then, are the implications for those trying to change a pattern of practice which is complicated by a long history of stigma, and a stigma which has shifted so subtly that many practitioners may not even be aware of how pervasive it is in their practice.

### **Limitations of the Study**

There are a number of limitations to the research. As previously discussed, the survey sample was too small to allow for in-depth analysis, particularly around comparing and contrasting the answers of sub-groups. Similarly, while it was theorized elsewhere in the paper that social work's application of family systems theory might lead social workers to better appreciate outcomes of family involvement, this cannot be assessed as so few social workers participated in the research.

A potential limitation of the questionnaire was that questions around knowledge of policy could have been misinterpreted by some of the participants. Such misinterpretations could have affected the assessment of policy awareness by clinicians. The interviews had two significant limitations. While some themes could be found within the data, each participant often had a very

different perspective from his/her colleagues. This suggests that a plethora of other very unique perspectives exist among mental health professionals; it would take a much larger sample to determine what could accurately be generalized about the group as a whole and the various sub-groups within it. The practice experience of the interviewees was also unbalanced, with four who had over 15 years of experience and one with much less.

One thing which became clear during the process was that the research question should have been more precise. Unfortunately, the lack of precision of the research question often does not reveal itself until the study is underway. The question asked in very general terms if “an” education module could create change, failing to recognize that the answer would be affected by the length of the time available for the workshop, the format used, or even whether or not it was well-received. It became clear as well, when preparing the literature review, that more specific parameters would have been helpful for the sake of comparison to previous models and for future training.

There were some concerns from the beginning of the module development that the time allotted for the workshop was insufficient, and this constraint did significantly affect the design. For instance, increased small group interaction would have been possible and would certainly have been included, which is precisely what some interviewees felt was lacking in the module. This limitation very likely impacted the outcomes; as participants suggested, an altered format would have engaged them more. Fortunately, as the research question was modified from trying to create and assess change to examining clinicians’ beliefs, practices, and perspectives on the module in more detail, the issue of effectiveness of the module became less relevant, and very interesting data arose from the process.

When considering research outcomes, it is clear that having the support of the VCMHS Coordinator was helpful and facilitated the process. However, it should be recognized that relying on another person to make all of the plans was also a limitation. This type of planning meant that the researcher did not have the opportunity to plan things in other ways. For instance, participants might have been recruited in a different setting which might have allowed for a longer presentation, and one which could have been more interactive as a result. These qualities might have enhanced both openness to learning and learning itself, perhaps have had more impact on the practice of participants.

The results of this research are limited in terms of generalizability. The results suggest an understanding of what some practitioners believe about families and whether or not they engage with them regularly. The research findings also illustrate the existence of a continuum of information-sharing practices and perspectives on families. It would not be possible to extend the findings of the research with such a small sample. However, the results mirror the research outcomes documented in the literature review. Those academic and practical undertakings spawn from other countries in the English-speaking world such as the UK, the US, and Australia (Chen, 2008; Rowe, 2010; Wynaden & Orb, 2005), and similar activities are likely occurring elsewhere as well. This fact indicates that issues around information-sharing in VCH are certainly not isolated to Vancouver. Elsewhere the challenges remain the same, but regions will differ in their practices based on a number of factors including local training, initiatives, leadership, and specific laws and policies.

In Vancouver, given the goals and initiatives of VCMHS, families and their supportive networks may not need to ask themselves forever *if* clinicians will integrate policy and evolve

their practices with families. Instead, they might ask *when* they will do so, how long it may take for such a transformation, and how it will be experienced by everyone involved.

### **Conclusion**

This research examined a topic which could be perceived as a “private trouble” for the many families who are isolated and silenced. However I argue that this issue is a “public issue”, one so entrenched in society and the mental health system that it spans parts of the globe. At face value it seems to be about practice preferences in mental health professionals, but it is more accurately described as being about stigma and blame. On closer and deeper examination, exclusionary practices can be seen to affect not only the families who are struggling but the well-being of the clients themselves. Therefore, the lack of family involvement is still of concern even if the needs of families are ignored. As practice improvement in health care is important to ensure high quality treatment for clients, including families in practice is important in moving toward this goal. In reviewing the research process and the module development, the creation and presentation of the module was beneficial and resulted in significant learning. The module will be modified to suit the needs of other learners and used again in the future. The feedback gathered during the research will be used by VCMHS and this researcher to make improvements to the presentation which will make it more effective.

The data which was gathered had some interesting complexities and contradictions. The results were quite revealing regarding the state of family involvement in the mental health system within Vancouver Coastal Health, and presumably within the Vancouver area. While some of the results had been previously documented in the literature, the research is able to locate the same outcomes much closer to home.

Efforts to create change in information-sharing within VCH are continuing. As a researcher and a practitioner, I have been invited to keep working with VCMHS towards this goal. It was the conclusion of VCMHS' Family Advisory Committee (FAC) that information-sharing is the gate-keeper to higher levels of family involvement. This is quite insightful, for as long as confidentiality guidelines are misunderstood or purposefully used as a barrier to communication, families are far too easily shut out of an involvement which is their need and their right. Therefore, with new educational opportunities there is much hope, and the hunger amongst some practitioners for more education on the subject is exciting. The challenge remains in providing this learning in a way which is truly palatable and engaging, and leads to self-reflection and self-awareness. This research, in spite of its challenges—or perhaps because of them—is replete with lessons for anyone trying to understand where best to go from here.

It should not be ignored, of course, that those at the point of direct contact with both client and family members face ethical and logistical dilemmas on a regular basis. They face innumerable case situations, each challenging, requiring careful consideration and application of clinical judgment. It is in the context of this complexity that the challenge they face needs to be understood. The next task of the leaders or educators, then, is to meet the clinicians 'where they are situated' and help them to manoeuvre these challenges, changing perspectives on families with sensitivity, in way which is tangible. Ultimately, increased family involvement can have a number of positive outcomes: better experiences on the part of families, enhanced well-being for clients, and work with clients which becomes more effective and rewarding. Furthermore, clinicians may need to turn to policies and guidelines to guide their practice. By being receptive to what family-involvement can add to their work, and what this practice will ultimately add to the lives of their clients, clinicians may just be surprised by the outcomes.

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*Appendices*

- A. Certificate of Research Ethics Board Approval
- B. Sample of Module Material: Case study discussed in the module
- C. Pre-Module Questionnaire
- D. Interview Questions
- E. Sample of Module Material: Paragraph of compiled quotes
- F. Sample of Module Material: Handout provided to participants

*Appendix A*  
*Certificate of Research Ethics Board Approval*



**Certificate of Research Ethics Board Approval**

Contact Person Clara Sitar	Department Social Work	Protocol 419
Co-investigators Adrienne Chan, Gloria Baker		
Title of Project Families and Information Sharing in Mental Health		
Sponsoring/Funding Agency None		
Institution(s) where research will be carried out University Of The Fraser Valley; Vancouver Coastal Health Authority		
Review Date: 22-Nov-11	Amendment Date: 15-Nov-11	Original Approval Date: 17-Oct-11
Approval Term: 17-Oct-11 - 16-Oct-12		
<p>Certification:</p> <p><i>The protocol describing the above-named project has been reviewed by the UFV Research Ethics Board and the procedures were found to be in compliance with accepted guidelines for ethical research.</i></p> <div style="text-align: center;">  </div> <p>Sandra Smith, Chair, Research Ethics Board</p> <p><i>NOTE: This Certificate of Approval is valid for the above noted term, provided there is no change in the procedures or criteria given.</i></p> <p><i>If the project will go beyond the approval term noted above, an extension of approval must be requested.</i></p>		

*Appendix B*  
*Sample of Module Material: Case study discussed in the module*

*Note: This case study resulted in a pathologizing approach from participants in both of two workshops where it was used as a learning tool. Notably, the groups pathologized the family in different ways. The outcomes are not provided for ethical reasons.*

**Paul\***

- Paul is a 32 year old Caucasian man born in Ottawa.
- He became homeless and was subsequently diagnosed with schizophrenia disorder.
- He experiences much paranoia and was estranged from his family for many years.
- He is very guarded about his experiences and the process of diagnosis was challenging.
- The last time he was discharged from extended leave, he was lost to follow-up.
- He is back in contact with a team after a hospitalization.
- He reconnected with his mother, Sue, during that time.
- His illness is currently being managed by medication. However, he has unwanted side effects such as weight gain.
- His family pays for him to have a car and for his condo, and now sees him regularly.
- He does not want his family involved in his treatment.
- Sue, his mother, comes across to the CM as anxious.

Questions

- Would family involvement benefit the client?
- Is the family a caregiver in this case?
- What might be outcomes of involving family over an extended period of time?
- How could the family become participants in Paul's care?

\*Name and identifying details have been changed for anonymity.

*Appendix C*  
*Pre-Module Questionnaire*

**ID number (birth date YYYYMMDD, e.g. 19650829) or other memorable date\_\_\_\_\_**

This questionnaire should take 15 minutes to fill out.

*Demographic Information*

Please select the appropriate choice:

I am a:

Social worker  
Psychiatric nurse  
Clinical counsellor  
Psychiatrist  
Occupational therapist  
Other

I have been working in this or a similar role for:

1-3  
4-6  
7-10  
11+ years

*Perspective and Practice Questions*

Please select the degree to which you agree with these statements, by selecting from:

1 strongly disagree  
2 disagree  
3 neither agree nor disagree (neutral)  
4 agree  
5 strongly agree

1. It would be easier to work with families if the rules on when and how to involve them were clearer.
2. It seems as though the families of my clients are frequently over-involved in caring for them, causing problems for my clients.
3. I see value in working with families, as they have a lot to offer us.

4. I worry about losing the trust of my client if I talk to their family.
5. “Toxic” or “problem” families are a common occurrence in our work.
6. I work with families on a regular basis, with positive outcomes.
7. I work with the families of a large proportion of my clients.
8. Sometimes it is easier not to work with families.
9. When I have worked with families, I have found their input and insight to be helpful.
10. It is often in the best interest of the client that I do not interact with their families.
11. Working with families is easier said than done.
12. Applying discretion in my practice is the hardest part of information-sharing with families.
13. I hesitate to be in contact with families because they can be a major contributor to my clients’ instability.
14. Thinking that I want to (or I should) increase my work with families is one thing, but actually doing it feels a bit overwhelming.
15. I have to maintain the confidentiality of my clients at all time unless suicide or homicide is imminent.
16. I struggle with knowing when I am, or am not, allowed to talk with clients’ families.
17. When we talk about a client being at significant risk for harm (or being in need of protection), we are basically talking about suicide or other form of death/major injury.
18. Vancouver Coastal Health (VCH) policies allow, and even encourage, me to work with families.
19. I feel “stuck in the middle” when I interact both with clients and their families.
20. Case managers working at the Early Psychosis Intervention (EPI) Program are allowed to work with families because their clients are under age; as our policies are different in adult mental health I cannot practice with families in the same way they do at EPI.
21. Lately I have been thinking about working with families more than I have in the past.
22. I have the tools I need to work with families.

- 23. Applying confidentiality guidelines is so tough because each case is uniquely challenging.
- 24. Sometimes I worry that by speaking to families I will break confidentiality and get in trouble/be reprimanded.
- 25. Involvement with families should be limited.
- 26. I feel confident applying the concept of “continuity of care” in order to work with the families of clients towards care plans or case management.
- 27. The family of my client is also my client.

*Additional comments*



*Appendix D*  
*Interview Questions*  
*(Semi-structured, exploratory)*

What did you take away from the workshop...

- About families?
- About disclosure?
- About continuity of care?
- About risk and protection of clients?
- About definitions of caregivers?

Did you experience any negative reactions to the workshop? What were they?

In general, did you feel it was worthwhile for your practice?

What was your reaction to the idea of family-blaming as it was presented in the workshop (which was that it has changed but still exists in subtle ways)?

Has anything changed for you since the workshop? (ie. thinking about wanting to apply the learning, applying the learning ,etc.)

How do you see that you might integrate the new learning into your practice (if this is an expressed intention of the participant)?

Do you think there is a gap between belief/feeling and doing? What is in the gap?

What do you think needs to happen to move further towards family involvement?

What was your reaction when I talked about the value to clients of involving the family? Do you see benefits to the client, or is family involvement mainly for the benefit family?

Do you feel that your colleagues share your views? If not, in which ways? Is the view profession-based in any way?

*Appendix E*

*Sample of Module Material: Paragraph of compiled quotes  
(Contains a family-blaming slant)*

“Caregivers can easily find themselves enmeshed with their ill relative and the illness. Problems can arise if this level of involvement is allowed to persist (p. 34).” “Faced with very real worries about the increased risk of school failure, substance abuse, and criminal activities, it is easy to fall back into the role of nurturing parent. But it’s important to remember that this can create dependency (p. 48).” “As your family member begins to feel better, they will likely need less of your help. Some types of caregiving can be very helpful at one stage of recovery but unhelpful at another. There will be a point where it will be more helpful to start backing off. Helping a person with psychiatric difficulties [...] can lead to patterns of caring that quietly foster an exclusive reliance on the family. Your challenge is to recognize when you need to change the type of help you provide in order to prevent your well-intentioned help from becoming an obstacle to recovery. The goal of caregiving is to provide ‘help that helps’ instead of ‘help that hurts’ (p. 57).”

“We offer a word of caution, however. In reviewing the literature, we found a wealth of information about family support in the early stages of mental illness, but very little with respect to later stages. (p. 57).”

*Family Self Care and Recovery from Mental Illness*  
Mood Disorders Association of British Columbia, 2008

## *Appendix F*

### *Sample of Module Material: Handout provided to participants (Explains policies which support disclosure)*

#### **MENTAL HEALTH ACT – QUOTED PASSAGES**

From Guide the Mental Health Act (2005), Ministry of Health

#### **CRITERIA FOR INVOLUNTARY ADMISSION**

##### Appendix 3

**3** – Requires care, supervision and control in or through a designated facility to “prevent the person’s...substantial mental or physical deterioration” OR “for the protection of the person...or the protection of others.”

The person must meet criteria in 3.a. or 3.b.

**3.a.** Prevent the person’s substantial mental or physical deterioration. There must be information that without treatment this person will likely deteriorate to the point that they would qualify under 3.b. -- they would need the protection of an inpatient setting. Helpful information for forming this opinion might include a previous history of acute episodes with significant deterioration and current symptoms that suggest similar deterioration is likely to occur.

**3.b.** Requires care for the protection of the person or the protection of others. The B.C. Supreme Court (McCorkell v. Riverview Hospital) has ruled that the term “protection” goes beyond physical dangerousness. Physical, social, family, vocational or financial harm may be included in the definition of “protection” from serious harms caused by a mental disorder. Protection of self can include non-physical harms, as mentioned above, or suicidal threats or gestures. Protection of others does not need to be evidenced, for example, by a physical blow. Threats or delusions can also be evidence of a need for protection.

#### **ASSISTANCE FROM RELATIVES AND OTHERS IN OBTAINING TREATMENT**

##### Appendix 2

Symptoms of behaviour indicating that substantial deterioration is likely to occur or that protection is needed may not be clearly evident during the physician’s examination. To help provide evidence, it can be useful if family members and others keep notes on the person’s symptoms and behaviours.

...Incidents or behaviour showing indication of:

- a) Mental disorder
- b) Need for psychiatric treatment
- c) Prevention of substantial mental or physical deterioration
- d) Need for protection of self or others or potentially harmful behaviour or symptoms  
(Examples include threats, violence, paranoid delusions, command hallucinations, irrational wasting of money, deteriorating physical condition, likelihood of or losing a job, dropping out of school, grossly unsanitary living conditions, and suicidal ideas or behaviours)
- e) Unwillingness to accept voluntary treatment

#### **9.0 Discharge (from Extended Leave)**

Patients, relatives and others involved in the patient’s care in the community should be included in discharge planning and informed of the discharge date. This will provide support for vulnerable persons upon discharge and is important to continuity of care.

**Question 25**, page 17: Is it true my son's doctor cannot tell me anything about my son, who has been involuntarily admitted to a designated facility?

It is preferable for a person to consent to the release of information. However, where disclosure is required for continuity of care or for compelling reasons, such as if someone's health or safety is at risk, a public body such as a hospital should release necessary personal information without the client's consent. See Appendix 13 (FOIPPA Fact Sheet).

### **Appendix 13** (FOIPPA Fact Sheet)

In deciding whether or not to disclose the client's personal information to the family, the health care provider should consider whether the family's "need to know" outweighs the client's wishes. If the provider believes it is in the best interests of the client to disclose personal information to the family so they can provide care to the client, the health care provider may do so [section 33.2(a)]. The provider should exercise caution to ensure only necessary information is released. Reasons for disclosing the client's personal information should be recorded in the clinical file.

### **FOIPPA FACT SHEET: QUOTED PASSAGES**

*This fact sheet relates to mental health and is in plainer language than FOIPPA*

Public bodies may release necessary personal information to third parties without the consent of the client where disclosure is required for continuity of care or for compelling reasons if someone's health or safety is at risk.

Public bodies may disclose personal information to health care professionals, family members, or to other persons such as friends and relatives, involved in a client's care.

Although public bodies have authority to disclose personal information, they also have a responsibility to minimise invasion of client privacy. Wherever possible, consent for the release of personal information should be obtained from the client. Each release of information must be considered on its merits, in keeping with the standard of reasonable clinical judgment.

The provider must strike a balance between the need to share the client's information with a family member or other third party who is involved in the client's care and the need to safeguard the client's trust and privacy.

A client's history, their health, and the care provided by the third party are mitigating factors which the health care provider needs to consider.

It is recommended that health care providers explain the limits of confidentiality early in the provider-client relationship.

When disclosing client information to third parties, document what information is being released, to whom it is being released, and the reason the third person "needs to know" the information.

There are no definitive rules regarding the release of personal information. Releases of personal information need to be considered on a case by case basis.

Obtaining consent from the client is generally preferred when releasing any personal information to a third party. However, health care providers do encounter circumstances when consent is not viable. [...] When disclosing without consent, the practitioner must be confident that the release of information is in

the client's best interest, is necessary for the continuity of care of the client, and only the information that is absolutely necessary is released to the third party.

***FREEDOM OF INFORMATION AND PROTECTION OF PRIVACY ACT  
& CONTINUITY OF CARE***

*Plain language interpretation of the quoted FOIPPA passages below*

This act talks about using information for a consistent purpose. In our language, that refers to the use of personal information for continuity of care. Continuity of care is sharing information about a client with another party (another professional or another caregiver / designated person in the life of a client) for the purpose of helping that client receive appropriate care in another setting from ours.

That can mean gathering information from the client or caregivers (such as for an admission to hospital), or providing information to clients or caregivers (such as for a discharge from hospital or for ongoing treatment).

***FOIPPA QUOTED PASSAGES [RSBC 1996] CHAPTER 165  
PART 3 PROTECTION OF PRIVACY***

*(Current to Dec 14, 2011—this date is repeatedly being extended)*

**27.1(a)1.** A public body must collect personal information or cause personal information to be collected directly from the individual the information is about unless the collection of the information is necessary for the medical treatment of an individual and it is not possible to collect the information directly from that individual.

**28(b)** If the personal information will be used by or on behalf of the public body to make a decision that directly affects the individual, the public body must make every reasonable effort to ensure that the personal information is accurate and complete.

**32** A public body must ensure that personal information in its custody or under its control is used only:  
(a) for the purpose for which that information was obtained or compiled, or for a use consistent with that purpose.

(b) if the individual the information is about has identified the information and has consented, in the prescribed manner, to the use.

**33** A public body must ensure that personal information in its custody or under its control is disclosed only as permitted under section 33.1 or 33.2.

**33.2(a)** A public body may disclose personal information referred to in section 33 inside Canada for the purpose for which it was obtained or compiled or for a use consistent with that purpose.

\*Note from *Guide to the Mental Health Act*, p. 126: “The requirement for notification does not apply to Section 33.2(a)”

**34** A use of personal information is consistent under section 32 or 33.2 with the purposes for which the information was obtained or compiled if the use:

(a) has a reasonable and direct connection to that purpose, and

(b) is necessary for performing the statutory duties of [...] the public body that uses or discloses the information or causes the information to be used or disclosed.

### **FOIPPA IN “PLAIN LANGUAGE”**

*(The direct quote is followed by an interpretation)*

FOIPPA 27.1.a.1 You must collect information directly from the client unless it is not possible to get it from that person and the information is required for medical treatment.

*This means: As the person trying to provide the best treatment to the client, if you know you cannot get particular information from him, you may get it from another source.*

FOIPPA 28 “Make every reasonable effort to ensure that the personal information is accurate and complete” when making treatment decisions.

*This means: To make treatment decisions, you need to gather accurate information—caregiver collateral is needed to ensure this.*

FOIPPA 32.a Information on the client can be used by the practitioner when: a) it is necessary for continuity of care, or b) the client has consented.

*This means: Client information can be used with consent OR for continuity of care without consent.*

FOIPPA 33.c A practitioner may disclose client information for continuity of care. The requirement for notification does not apply.

*This means: You may disclose client information without telling the client.*

### **DISCLOSING**

The FIOPPA Fact Sheet states that:

- “There are no definitive rules”
- The decision is on a “case by case basis”

This serves as a protection in your practice, particularly when you apply your best clinical judgment and consult with the manager or your colleagues when you are unsure.

*Document everything and reflect for next time.*